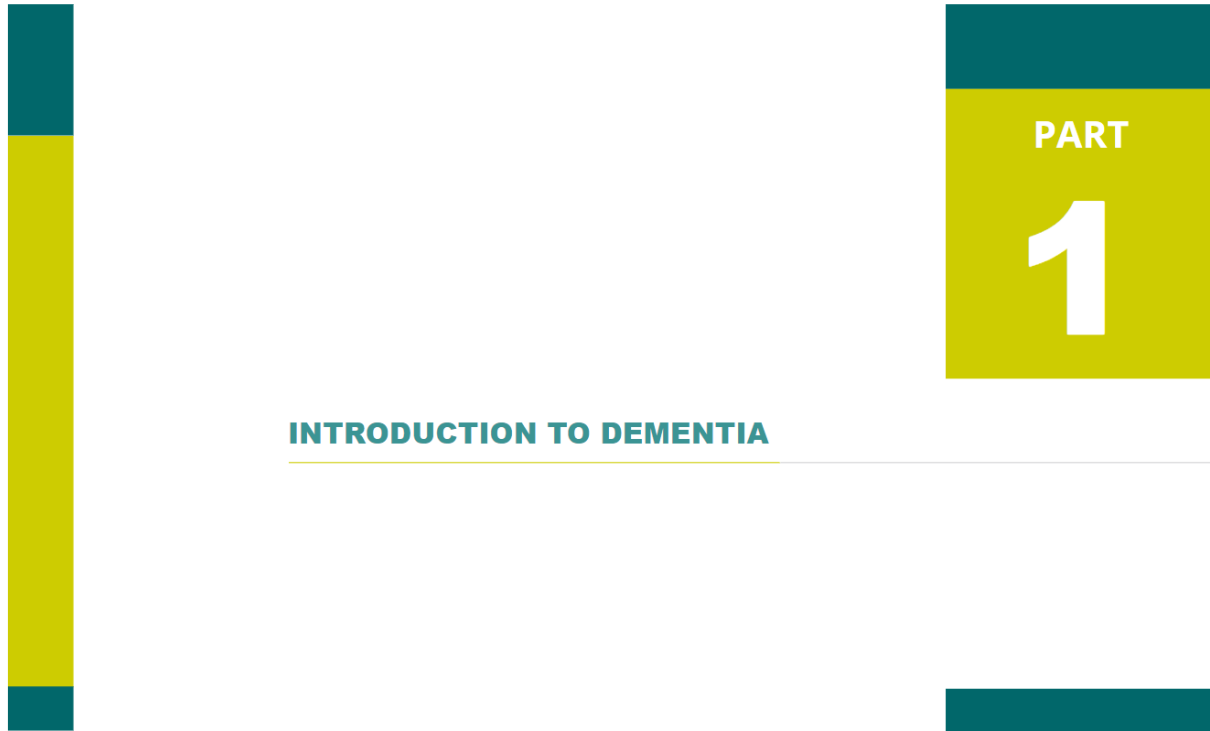


# iSupport for Rare Dementias

## Part 1 Introduction to dementia



### INTRODUCTION TO DEMENTIA

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## Session 1. Introduction to dementia

### **Why is this session important?**

Dementia is a disease that can be overwhelming for the person with dementia, but also for you as a carer. There are many myths about dementia and learning more will help explain some common misunderstandings.

### **How will this session help me?**

This session helps you to understand the basics of what dementia is and how it affects someone. This information is essential when you are a carer.

### **What will I learn?**

1. What is dementia?
2. Types of dementia
3. What happens to people with dementia as the disease progresses?
4. What to do if you think that the person you care for has dementia?
5. Getting a diagnosis
6. How to reach out for help
7. What is the focus of this Internet support tool?

### **1. What is dementia?**

Dementia occurs as a result of a disease process that increasingly damages the brain over time. Dementia affects all groups of society and is not linked to social class, gender, ethnic group, or geographic location. Dementia is not a part of normal ageing. Although dementia is more common among older people, younger people can also be affected.

### **2. Types of dementia**

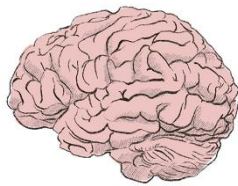
There are many types of dementia, the most common types are Alzheimer's disease and vascular dementia. There are many types of rarer dementias. These often affect younger people and initially present differently to the more common dementias but can overlap later on. This guide will focus on dementia with Lewy bodies, frontotemporal dementia, primary progressive aphasia and posterior cortical atrophy.

## **Dementia with Lewy bodies**

Dementia with Lewy bodies is similar to Alzheimer's disease in that it is caused by deteriorating and dying nerve cells in the brain. It takes its name from abnormal deposits of protein - Lewy bodies - in the nerve cells of the brain. Approximately, half the people with Lewy body disease also develop signs and symptoms of Parkinson's disease. Common symptoms of Lewy body disease are:

- Movement difficulties
- Concentration problems
- Hallucinations
- Sleep disorders
- Changes to memory and decision-making abilities

## **Frontotemporal dementia (FTD)**



In frontotemporal dementia (FTD) (previously known as Pick's disease) the damage is usually concentrated in the front part of the brain. In the beginning, personality and behaviour are usually more affected than memory. There are two types of FTD: behavioural variant FTD and primary progressive aphasia.

## **Behavioural variant frontotemporal dementia**

This form of FTD mainly affects a person's personality and behaviour. Common symptoms of behavioural variant FTD can include:

- Disinhibition
- Lack of motivation
- Concentration problems
- Loss of empathy
- Repetitive or obsessive behaviours

## Primary progressive aphasia (PPA)

Primary progressive aphasia affects the language processing part of the brain. Common symptoms can include:

- Slow or jumbled speech
- Difficulties remembering words or names
- Swallowing problems

## Posterior cortical atrophy (PCA)

In posterior cortical atrophy, the damage is localised in the part of the brain responsible for processing visual information. Common symptoms include:

- Difficulty recognising faces
- Problems with judging distances
- Light sensitivity
- Difficulty reading

### 3. What happens to people with dementia as the disease progresses?



Every person is unique and dementia affects people differently. No two people will develop the same difficulties in exactly the same way. It is not just the brain damage that determines how dementia affects someone, but also other factors including an individual's

personality, life course, general health and functioning, and living environment.

## **Dementia has stages**

Dementia symptoms can range from small behaviour changes, to significant difficulties in thinking that mean the person requires help to manage daily activities. It can be helpful to view dementia as a series of stages to understand the illness but it's important to remember that everyone progresses differently. People with rarer dementias may move through the stages faster than those with more common types of dementia, like Alzheimer or vascular dementia.

In the early stage of the disease, people with rarer dementia may show changes in their personality and their behaviour, difficulties making decisions and planning, and might become more withdrawn. These changes in behaviour can be upsetting and distressing to the person with dementia and those around them.

As their dementia progresses, the symptoms will increase and the person with dementia may be in need of help with daily activities such as shopping, dressing and washing, and may no longer be able to recognise relatives or friends. This level of care might become harder for relatives and friends to provide. Moving into a care setting might become an option or necessity, and should not be seen as a failure by those who provided the care.

### **Keep in Mind**

Stages can only provide a rough guide to the progress of dementia, everyone experiences dementia differently. Not everyone with dementia will have all of the symptoms listed and the symptoms may appear at different times.

## 1. Activity

Here are some common things that may happen to people with rare dementias. Do you think that your family member/ friend/ the person that you care for experiences any of the following?

*Please select all that apply.*

Does the person you care for...		Examples
Experience changes in vision or co-ordination?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Misjudging distance- knocking over objects or crashing into them</li> <li>• Have blurred vision or words moving on pages</li> </ul>
Find it difficult to perform daily activities?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Experience difficulty managing their money and finances</li> <li>• Having difficulties carrying out their work</li> <li>• No longer able/confident to drive</li> </ul>
Struggle to identify time or place?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Forgetting the date and time of appointments</li> <li>• Getting lost in familiar places</li> </ul>
Move differently?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Changes to balance, steadiness, and mobility</li> <li>• Increased clumsiness</li> </ul>
Communicate differently than they did before?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Difficulty finding the right words</li> <li>• Repeating themselves</li> <li>• Hesitant, vague, or over-detailed speech</li> </ul>
Withdraw socially?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Showing a decline in social activity, less willing to socialise</li> <li>• Lacking urge to do something, no initiative</li> </ul>
Show changes in feelings or personality?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Becoming more anxious than before</li> <li>• Showing new impulsive or obsessive traits</li> </ul>

## Remember

Experiencing some or all of these symptoms over a period of time does not mean that someone has dementia. But if this causes concern, please visit your GP so they can assess whether there are other reasons why the symptoms might have appeared.

### 4. What to do if you think that the person you help care for has dementia?



If you think that a family member or friend may have dementia, a good first step is to make sure that they see a medical doctor. The doctor will examine their body and brain functioning.

It will be important to rule out whether the person's symptoms are caused by other treatable conditions such as depression, urinary tract infection, medication side effects, lack of vitamins

or a brain tumour.

The medical doctor might refer the person on to other specialists who can help work out whether the person's symptoms are part of dementia or are caused by something else. Only a medical doctor and a team of specialists can do this, not this manual.

## 2. What could you do?

What is the first step if you think that a family member or friend has dementia?

- **As a first step try and talk to the person about your concerns and see what they think. They might be concerned too and be willing to contact the GP.**

If they are reluctant to call the GP, you can make an appointment with their GP and explain your concerns. This way the GP is alerted and can consider this information when they next see your friend or relative. This is the best first step if you have not done so already.

- **Call the Dementia UK helpline: 0800 888 6678 (Open 9am-9pm, Monday- Friday and 9am-5pm, Saturday and Sunday)**

Your call will be answered by an admiral nurse who can provide professional support and advice.

- **Call a friend or relative**

Friends and family can offer support, and help think through what can be done.

## 5. Getting a diagnosis

Because rare dementias are less common, professionals might not be as familiar with these types of dementia especially if the person is younger (under the age of 65), it can be harder to get a diagnosis. The presentation in younger people and variation in symptoms can mimic other conditions. For example, lack of motivation often seen in frontotemporal dementia can be mistaken for depression and may lead to a delayed diagnosis or a misdiagnosis.

It is also possible to receive more than one diagnosis, such as dementia and anxiety or depression.

## **6. How to reach out for help**

It is important to know that you may not be able to provide all the care that the person living with dementia needs by yourself, especially as things get more complex over time. So, we encourage you to reach out to family members, friends, and professional organisations or services for help.

There are several resources that may be very helpful, some are free while others are not. Below are some useful links for information, support and care that is available in the UK and could benefit the person you care for as well as yourself.

- <https://www.raredementiasupport.org/>
- <https://www.youngdementianetwork.org/>
- <https://www.lewybody.org/>
- <https://www.alzheimers.org.uk/>

## **7. What is the focus of this Internet support tool?**

The focus is on you, a carer of someone with dementia.

Not everyone supporting a person with dementia will identify as a carer however, for the purposes of iSupport, we use the term carer to describe people supporting someone with dementia. This includes anyone offering support to a person living with dementia, including friends, family or neighbours.

Dementia can be overwhelming. For this reason, iSupport provides you with support to cope with caregiving on a day-to-day basis. It is really important that you not only take care of the person living with dementia but also take care of yourself. iSupport will provide you with information and suggestions on how to respond and manage certain situations that might happen with people with dementia so that you are aware and can practice how you could respond in such situations.

[Alzheimer's Disease International](#) member webpage is a good place to start to find a local Alzheimer's Association.

## Keep in Mind

- Dementia affects a person's brain.
- Dementia is common, especially in older people but over 70,000 people with dementia in the UK are under 65.
- Dementia is a disease, not a part of ageing.
- As a first step it is important to see a medical doctor, if possible.
- It is important for you to take care of yourself, not only the person you care for.
- iSupport can support you as a carer.

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